



*NEWSLETTER OF
THE LONG ISLAND CHAPTER OF THE
TOURETTE SYNDROME ASSOCIATION*

P.O. Box 615
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PRESIDENT'S MESSAGE

Message From the Chair

Hello Everyone,

A belated Happy New Year to All! This newsletter marks one year since the new Board's tenure at LI-TSA began. During the past year, we have held several events, including a general meeting, a bowling event, the wonderfully inspiring presentation by Susan Conners, the pre-screening event of the HBO documentary, "I have Tourette's, but Tourette's doesn't have me," and a fundraising event at Bloomingdale's, which raised more than \$1600.00 for our chapter. These events were successful because of the efforts and participation of our wonderful members, and their families. Thank you, all!

Thanks to Keith Josephson, we have also gotten our website back on track, but hope to make it more attractive and active as time goes on. If any of our members has expertise with website management and would be interested in taking on this very important responsibility, please let us know. We are still getting out feet wet, and need all the support we can get!

Our Education/Advocacy Chair, Jane Zwilling, has done a phenomenal job over the year going into many Long Island Schools to educate faculty and staff about TS, about how to make life in the school environment easier and more fulfilling for children with TS, and how to improve the classroom environment for all. And, we are all so very proud about how Jane's daughter, Jen Zwilling, has been making headlines with her own most outstanding efforts as our Youth Ambassador. Read more about Jen's achievements inside.

We have increased our membership, and many of our members are expressing a very welcomed interest in volunteering to help with the chapter's activities. We can always use people willing to share their talents with us, so let us know what you can do, and be a part of the positive impact we are having on all LI families with TS. In particular, we need articulate individuals who would like to be trained to go into schools and do presentations for faculty and staff. Jane has essentially been doing all of these presentations herself, but the demand for them is increasing. That is a very good thing, and we would hate to have to turn down any requests. Contact us if you feel this is

something you think you can, and have time, to do. We will open this year's events with a General Meeting on March 22nd, so mark the date on your calendars. We have a very exciting speaker lined up for the evening, and will outline our goals for the year, so please be sure to come. See inside for further information about John Golder, Esquire, who specializes in Special Education Law, as well as venue and time details.

This year we are hoping to increase the number of social gatherings for families to at least four. We welcome ideas or venues that any of you have for these socials. We plan to have our first Social in April (see inside for details), and at least one seasonally, thereafter. It would be very helpful, and offset mailing costs for these socials and special events, if we could generate an e-mail list for as many members as possible. If you would like to be on this list, please send your e-mail address to our new e-mail address: **LongIslandTSA@aol.com**.

Last, but certainly not least, we are starting a very exciting new service. Many of our members have expressed a desire to have a child-support group to complement our parent-support group. I am very pleased to announce that we have found an excellent facilitator and a venue and will finally be starting this service on the first Friday in May. See inside for information about our very qualified facilitator, as well as location and time details. Of course, this service and the parent-support group, which will run simultaneously in the same facility, and are free to members.

As you can see, we have an exciting year ahead of us, and look forward to being of service to you in any way that we can. We are here for you, so let us know what we can do for you, AND how you might like to be a part of our team. I hope to see many of you at the General Meeting on the March, 22nd!

Lisa Filippi, Ph.D
Chair, LI-TSA

CHILD SUPPORT GROUP TO BEGIN SOON!

We are delighted to announce the long anticipated start of a Child Support Group for the Long Island Chapter. We are fortunate to have retained Evan Michaels, LCSW, of TSA National, as the facilitator. In his work at National, Evan has engaged in psychotherapeutic and educational social work with children, adults and families affected by TS. He has lectured on the disorder and published articles, as well. Thanks to the generous cooperation of our hotline manager, Julia Vinsky, we have finally found a venue with two rooms where we can hold both the parent and child support groups on the same night, so that more members will be able to participate in both of these important groups, which are free to members of LI-TSA. The appropriate age group for the children is 7-12 years. Please be sure to avail yourselves of this valuable new service, which will help your child cope better in all of his social and educational experiences. We hope that the convenient scheduling will allow more parents to attend the parent support group, and make this exciting addition to our services a win-win situation for all.

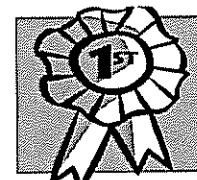
Child Support Group meetings will coincide with Sue Vitek's meetings for Free Parent Support Group on same evenings listed below and at same venue.

Meeting Dates: First Friday of the month beginning on May 5, 2006; then June 2, 2006; July 7, 2006; August 4, 2006; September 1, 2006, October 6, 2006, November 3, 2006 and December 1, 2006.

Place: DeMatteis Center, 1 Northern Blvd., Old Brookville located on the north side of Northern Blvd., just west of Route 107, past C.W. Post, opposite NYIT.



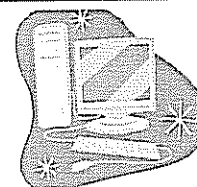
CONGRATULATIONS!!!



Director Ellen Goosenberg Kent of the HBO special "I Have Tourette's, But Tourette's Doesn't Have Me" has been nominated for the Director's Guild of America 2005 Outstanding Directional Television for Director and Producer. This nomination is Ms. Kent's first. At the January 28, 2006 announcement of the awards, DGA President Michael Apted said "With the landscape of television rapidly widening and productions becoming more complex and more visually ambitious, the role of the director is increasingly critical to the success of television programming." He went on to say, "The DGA Television Awards represent an opportunity for the Guild to recognize this vital role and to honor the broad range of excellence found in television directing today. As we celebrate the inauguration of the DGA Reality Television Award this year, I offer my congratulations to the first five nominees – their work is a strong testament to the importance of the director's role in this genre."

The LI-TSA Chapter also congratulates Ms. Kent for the outstanding job she has done to bring Tourette's to the forefront in this important film.

Remember to visit us on the web at : www.li-tsa.org
Check out these websites for important information:
www.schneiderchildrenshospital.org
aboutourkids.org



Students Participate in Filming for Youth Ambassador Program

As reported in Syosset/Jericho Tribune, Dec. 16, 2005

On Saturday, Dec. 10, 2005, 19 Jericho Middle School students and one Roslyn Middle School student participated in the filming of a training session for the National Tourette Syndrome's Youth Ambassador Program. The program was founded by 10th grade Jericho High School student Jennifer Zwilling with help from her older sister Amanda and younger brother Eric.

Jennifer's program is one in which "kids talk to kids" about Tourette Syndrome (TS) in an effort to raise awareness and understanding about this very misunderstood disorder that is characterized by sudden involuntary movements and vocalizations called tics.

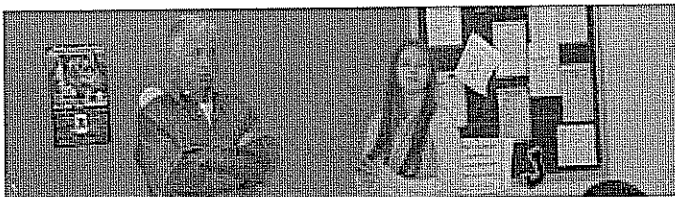
Jennifer began going into schools on Long Island as a 7th grader to raise awareness. She has since traveled to Westchester, Queens and even as far away as Virginia to talk to classes and grades of children.

This April, Jennifer will bring her program to the national level at the National Tourette Syndrome Association Conference in Alexandria, Virginia where she will be presenting to and training 30 teens from around the country to be youth ambassadors. Each ambassador will bring her program back to his or her own state, community, school and clubs.

Jen's goal is to convey the message to her generation that "by educating children with accurate information, we can help those with the disorder to be accepted and their behaviors to be understood."

Each teen who attends the training in April will take home a copy of the training video that was filmed this past Saturday at Jericho Middle School. The film will not only help the 30 new Youth Ambassadors, but will be distributed to schools all across the country. This will ensure that the information can be infused into every classroom, even if a youth ambassador is not available to present to the particular class.

The middle school students who participated as members of the model class were recruited, and volunteered their time as they spent a 6-hour day being filmed. These youngsters not only had the opportunity to learn about TS, but also the experience of taking part in a professional filming.



Jen Zwilling - Youth Ambassador

Education and Advocacy Committee Update

The Advocacy Committee has been traveling around Long Island presenting in-services to staff and faculties in Nassau and Suffolk County schools.

Each attendee receives a Participant's Guide that has a great deal of information on TS, its manifestations and suggestions in regard to accommodations.

In addition, each school is given a copy of the HBO Documentary, *I Have Tourette's But Tourette's Doesn't Have Me*, made available by the chapter, and a copy of the book *Quit It*, made available through National TSA.

Our student Advocates have also been to several schools. We were thrilled that Amanda Zwilling was able to help out with presentations when she was home on Winter break from college.

Our most exciting news; in December, Jen Zwilling was filmed as she did her presentation to a class of middle school students. The Youth Ambassador Training film will ultimately assure that the program can reach classrooms and students even when the Youth Advocates/Ambassadors cannot travel to their schools. The film is still in the editing room, but we will keep you posted on its progress.

As always, please contact us if you or anyone you know would like a presentation in your school, or if anyone needs help advocating for a student.

We hope to hear from you.

Thank you,

Jane Zwilling, Psy.D., Chair
Advocacy Committee

Jen Zwilling, Chair
Student Advocacy Committee

In Memorium - Joseph Carini

by: Lisa Filippi

It saddens me greatly to have to inform our members that on the evening of December 2, 2005, one of our most valued behind-the-scene members, Joseph Carini, passed away suddenly at his home, at the untimely age of 52. Joe, the husband of our Treasurer, Josephine Carini, was a major force in the reestablishment of the Long Island Chapter over the past year. He had ideas, energy and a sense of clarity that contributed greatly to getting us back on our feet. Joe also graciously arranged for the Board to have its meetings in the comfortable environs of the conference room at Sagemark, where he worked as an independent financial advisor, in the Reckson Building on Jericho Turnpike in Syosset. In addition to contributing ideas, Joe's role at board meetings was to keep us focused on the agenda, when we might easily have strayed off on some peripheral discussion. He also had a flair for quickly filtering through the minutiae, and getting to the heart of a subject under discussion. We will miss Joe's valued advice and his often-repeated favorite line, "Okay, let's get back on topic; what's next on the agenda?"

It was also thanks to Joe that we have been able to use the large conference room in that same building to hold several events and meetings during the past year. It was Joe whom many of you saw sitting on the stage with his son, Michael, during the discussion panel following our prescreening event for the HBO documentary, "I have Tourette's, but Tourette's doesn't have me." Joe was a dynamic and impassioned man, who was driven to help improve the lives of those around him. We share with his wonderful wife, Jo, and dear son, Michael, in the great loss of this very special man



Don't forget our **Info-Hot Line** which exists as a helping hand to the community.

We return calls promptly and provide medical and professional referrals as well as community resources. We can answer general questions on TS and associated disorders. Call us at (516) 876-6947.

MANY THANKS TO ALL THAT GAVE OF THEIR TIME AND MONEY IN SUPPORT OF OUR VERY SUCCESSFUL BLOOMINGDALES EVENT.

PLEASE DROP US A LINE AT

LONGISLANDTSA@AOL.COM FOR THOSE WHO WOULD LIKE TO DONATE THEIR TIME, MONEY OR GIFTS-IN-KIND. ALL EFFORTS ARE APPRECIATED AND NECESSARY TO KEEP US RUNNING.

MEDICAL CORNER WITH DR. LES LINET from: NYC Chapter Newsletter - Feb. 2006

Q I have TS. So does my brother. Whenever I see a drawer or a cabinet door open, I immediately get up and close it. My brother jumps up and touches the ceiling all the time. My therapist says my urges to close drawers and doors are compulsions. But she says my brother's jumping to touch the ceiling is a complex motor tic. Is she correct? How can you distinguish a complex motor tic from a compulsion?

A This is a great question. After you read this, you may know more about the distinction than do many psychologists and psychiatrists.

I will rephrase the question as follows: Repetitive behaviors in Tourette's syndrome and OCD: what are the differences?

Gilles de la Tourette Syndrome (GTS) and obsessive-compulsive disorder (OCD) share obsessive-compulsive phenomena. However, it may be impossible to distinguish a complex motor tic from a compulsion merely by observation. To make the distinction, the patient must be asked about the reported repetitive thought or action. The key is what is in the mind of the patient. The patient's answer will be useful to define whether the behavior was an obsession, compulsion, or "impulsion." The concept of compulsions and 'impulsions' is useful in distinguishing GTS and OCD patients.

For example, if your brother reports anxiety and goal-directedness, such as he has to touch the ceiling or something terrible will happen to his family, he is performing a compulsion. If you, on the other hand, report - as did one of my patients - that you like to close drawers and doors and that it feels right or gives you a sense of pleasure to complete such acts, then you are performing a tic. The distinction between obsessions/compulsions and impulsions is of importance in identifying Tourette-related vs. OCD-related repetitions.

A tic is more of an "impulsion." A compulsion, on the other hand, is related to anxiety or risk avoidance. A tic is done because it feels right. A compulsion is performed to reduce anxiety. The classic compulsion is repetitive hand-washing. The individual does not hand-wash because it feels right or gives a sense of pleasure. The hand-washing compulsion relates to anxiety or risk avoidance, e.g., that someone will be contaminated unless the patient hand-washes.

LI-TSA EVENT PICTURES

Night with Sue Connors



Sue Connors speaking about Tourettes on October 26, 2005

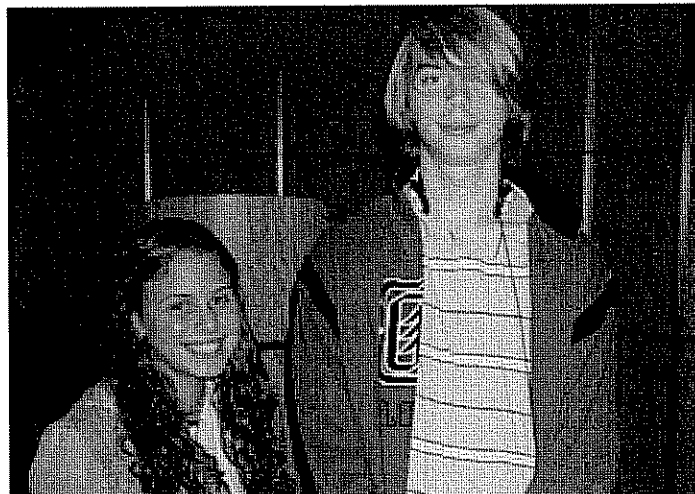
Night of HBO Special



Viewers of HBO Special "I have Tourette's But Tourette's Doesn't Have Me"



Sue Connors and Lisa Filippi, President of LI-TSA Chapter are all smiles at the meeting.



Jen Zwilling and Brian Wedeking

MARK YOUR CALENDAR - UPCOMING TSA GENERAL MEETING

Wednesday, March 22, 2006 - General Meeting

**Guest Speaker: John Golder, Esq.
Specialist on Special Ed. Law**

**St. Francis Hospital, DeMatteis Center,
1 Northern Blvd., Old Brookville
Across the street from NYIT**

LI-TSA is proud to present, John Golder, Esq. to speak to our members on the ins and outs of special education/special needs. His interest in special ed law was developed 8 years ago when his older and younger son were both diagnosed with autism and he realized the huge battle for services and education for his sons. Mr. Golder said "I may not know much about autism but I do know how to fight using the law to my advantage." Join us as he shares his experiences and expertise with us all.

The Continuing Saga of Shoh in Saga (Japan) Part 4

by: Lisa Filippi

From a very early age, as soon as Shoh could walk, in fact, he developed a very disturbing need to go for walks. It would have been fine if he wanted to take walks with us, but he seemed to prefer doing things on his own. He would just go and open the front sliding door in our Japanese home (they are very easy to unlock from the inside) and leave. He didn't have one particular place that he was attracted to; he would simply set off in a different direction every time. You might say, "What irresponsible parents!" And believe me, I felt that way more than once, myself. But it was truly uncanny how this tiny person could be in the next room happily playing with his toys, within my sight, while I cleaned up the kitchen after a meal, and be gone one minute later. He didn't wander off by accident and get lost; this was clearly deliberate. When he was still very young, we could find him pretty quickly, but as he got older and bigger, and able to move around with stealth and speed, the challenges to find him became greater. Thank goodness we had so many other older children; at least once every weekend there would be a search party, and Shoh would turn up in the least expected of places. Though, after awhile, we came to expect him to be anywhere! It was truly a predicament. With so many people in the house, we all thought that someone else was watching Shoh, so we had to assign "monitors".

A parent learns to do chores while watching a child; we must, or nothing would ever get done. We hear the child, and the familiar sounds of play and other activities that tell us all is well, and feel confident that the child is where he or she should be, in our case, safe in the family room. Then, for a split second the sounds are gone, and so is Shoh. That is how quick he was. He would walk straight in any given direction and not stop until we retrieved him. Luckily we were in a very safe little town in Japan, where children could still walk around, and neighbors would be friendly and kind. But, I had a problem with their being a bit too kind. He was fearless of strangers, and would walk into anyone's home uninvited. And, surprisingly, he would be admitted. He was very polite, and knew his manners, so he always took his shoes off at the front "genkan" (foyer). He would then walk into the home of these strangers, ask for a snack, receive a snack (???), and continue on his way out the back door. Now he was shoeless, as he continued on his journey.

Why these people never thought to stop him or try to find his parents, I could never quite figure out. Of course, as soon as we realized he was missing, all troops were called into action on a recovery mission. We all knew the routine: Tomoki, jump over the back fence and head west; Mom head east; Dad head north; Ken south; and Akiko, stay at home, and carry out surveillance from the second floor balcony, and be there in case he returned (he never did return on his own, though!). Our gray hairs increased, and Shoh got to know the neighborhood. We would usually find him within 15 minutes, that seemed like 15 hours, walking down a path, now, of course, without his shoes, We would have to retrace his steps, collect the shoes, and request the well-meaning neighbors to contact us if he should ever come their way again.

He was clever, though, and never went to the same house twice. One day, as we were on a search and all calling out his name, "Shoh, Shoh!", a neighbor on the next block (who I did not know) came out and asked, "Is he wearing an orange shirt?" When I responded in the affirmative, she told me, in very polite and helpful Japanese, with that practiced Japanese smile and nod of the head that could be conveying warmth or nothing at all, that he was using her toilet to make poopies. Embarrassed, annoyed and pleased all at once at Shoh's resourcefulness in managing to find a toilet when he needed one, I went into the home to find him happily singing on the toilet. It is hard to believe that this once fearless child, who would go up to and have a conversation with ANYONE is now quite suspicious of strangers, and needs a good bit of time to get used to relationships with new people.

I found after arriving in N.Y. that the special education people actually have a name for that kind of behavior. They suggested he go to a private special education school because he was a "wanderer", and wanderers could not be accommodated in a public school. Without chaining him to a fixture, it was impossible to contain him. He has wandered twice since our arrival here; the last event, which involved the police, seems to have cured him, and he, fortunately, seems to have outgrown that phase to a large extent. However, even at nine, we still cannot take him into large department stores, AND hope to do any shopping!

More next time.



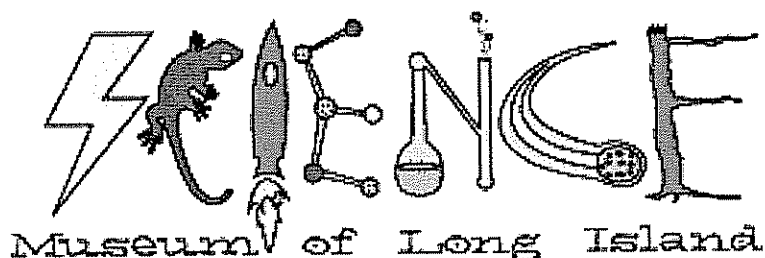
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MARK YOUR CALENDARS!

JOIN US FOR KID'S TIE DYEING DAY AT
SCIENCE MUSEUM OF LONG ISLAND

LI-TSA is hosting a kid's Tie-Dyeing Workshop on Saturday, April 29th, from 1:00 p.m. to 2:30 p.m. at LI Children's Museum. All are invited. Please RSVP ASAP via email at LongIslandTSA@aol.com.

1526 North Plandome Road
P.O Box 908 Plandome, New York 11030
TELEPHONE: (516) 627-9400

Directions: LIE to exit 35. North on Shelter Rock Rd. to Northern Blvd. (Rt. 25A). West on 25A to Plandome Rd. Turn right and follow to Museum.



NOTE: This study has been approved and is sanctioned by National TSA. Please feel free to contact the Child Study Center if you feel your child meets the criteria.